DOCUMENT RESUME

ED 303 940 EC 212 136

AUTHOR	Baumeister, Alfred A.
TITLE	The New Morbidity and the Prevention of Mental Retardation.
INSTITUTION	George Peabody Coll. for Teachers, Nashville Tenn. John F. Kennedy Center for Research on Education and Human Development.
SPONS AGENCY	National Inst. of Child Health and Human Development (NIH), Bethesda, Md.
PUB DATE	Aug 88
GRANT	NIH-HD-15052
NOTE	7p.
AVAILABLE FROM	Office of Information Services, The John F. Kennedy Center, Box 40, Peabody College, Vanderbilt University, Nashville, TN 37203.
PUB TYPE	Collected Works - Serials (022) -- Speeches/Conference Papers (150)
JOURNAL CIT	John F. Kennedy Center Research Progress; v7 n1 Aug 1988
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Acquired Immune Deficiency Syndrome; *Birth Weight; *Disadvantaged Environment; Economically Disadvantaged; Family Planning; *Health Needs; *Medical Services; *Mental Retardation; Models; Perinatal Influences; *Poverty; Pregnancy; Premature Infants; Prenatal Influences; *Prevention; Public Policy; Socioeconomic Influences

ABSTRACT

Efforts to prevent mental retardation have been encumbered by lack of scientific and technical knowledge, vague understanding of incidence and prevalence, and scarcity of resources to implement effective public policies. Scientific and social progress toward prevention has pursued a wavelike, erratic course, driven primarily by prevailing social, political, and economic climates and values. The new morbidity model of mental retardation focuses on mental retardation as a symptom or an outcome of underlying biological and social causes. Two primary associates of subsequent morbidity are poverty and low birthweight. Prenatal care is a major factor in improving pregnancy outcome and lowering incidence of low birthweight and prematurity. Access to basic services should be assured, including: prenatal, delivery, and postnatal care; comprehensive care through age 5; and family planning services. Another health problem which is impacted by socioeconomic disadvantage is pediatric acquired immune deficiency syndrome. Problems associated with the new morbidity have human and economic costs which far outweigh the costs of investing time and resources in research, treatment, and prevention. (JDD)

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RESEARCH PROGRESS

John F. Kennedy Center

for Research on Education and Human Development
George Peabody College, Vanderbilt University
August 1988

ED303940

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The New Morbidity and the Prevention of Mental Retardation

The "new morbidity" encompasses an array of behavioral, health, and school problems affecting a growing number of the nation's children and is strongly influenced by environmental and social factors, especially poverty. It is a focal concern of Kennedy Center Director Alfred A. Baumeister*, who has addressed this topic in numerous academic and public policy forums, including testimony before the Congress and the President's Committee on Mental Retardation. The new morbidity was the subject of Dr. Baumeister's January 1988 presentation in the Kennedy Center's Research Colloquia on Human Development; portions of those remarks follow.

* * *

Much of my effort has been devoted to research and treatment of children and adults affected by various types of handicaps, particularly mental retardation. The range of scientific, clinical, social, and conceptual problems thus encountered has been enormous—an experience shared by many. The complexity of these problems complicate our efforts to address them and necessitate a comprehensive approach to the problem of developmental disabilities. Ultimately, we must view the future in terms of prevention, not cure.

As one testifies before Congress over the years, consults with federal and state policy makers, and observes first-hand the enduring disabilities that people experience, one comes to understand that science and technology are embedded in an overriding constellation of factors that generate and moderate public policies. As a scientific culture, we purport to seek truth, but revelation of truth depends ultimately on moral, not scientific tests, emerging from confrontation of values. Those who wish to change the course of events must be cognizant of these values.

While prevention of mental retardation is not new, there has been more rhetoric than action. The President's Committee on Mental Retardation set a national goal to reduce incidence in half by the year 2000. A second objective is to reduce the incidence of mental retardation associated with "social disadvantage" to the lowest possible level by the end of the century. Several commentators have questioned whether these goals are realistic, due to lack of scientific and technical knowledge, vague understanding of incidence and prevalence, and scarcity of resources to implement effective public policies. While these observations may be valid, more fundamental moral issues lie at the heart of our collective social inability to respond to the call for prevention. The history of mental retardation in the U. S. reveals that progress, scientific and social, has pursued a wavelike, erratic course, rather than a continuous linear course of accumulation of knowledge. Public policies are driven primarily by prevailing social, political, and economic climates and values. Progress has been made in some areas while ground has been lost in others. In a recent review of state developmental disabilities plans for prevention initiatives, I found that budget cuts have forced many states to reduce services and to become crisis-oriented with respect to implementing services. Money and planning for large-scale prevention efforts are not available, a fact reflected in practically every state developmental disability plan. Less than 2% of our

*Professor of Psychology and Special Education, Vanderbilt University.

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resources is devoted to primary prevention. Suppose children play near a dangerous cliff and are in great risk of falling over, becoming seriously injured. We can erect a fence at the top, or we can put an ambulance at the bottom. In large measure, as a society, we have opted for ambulances, not fences.

Recently my work has focused on prevention within the concept of the new morbidity, specifically its association with poverty. In 1975, when Haggerty introduced the concept, conditions associated with it were described as behavioral and school problems among children and adolescents, as well as environmental risks, personal behavior such as drug and alcohol abuse, and accidents. We have expanded the concept to develop a model encompassing a wide array of psychosocial problems—adolescent pregnancy, learning disabilities, chronic health disorders, psychiatric symptoms, violence, suicide, and others. While none of these problems is new, the increasing prevalence of these conditions is alarming.

Discussions implicating socioeconomic status (SES) variables typically imply that concern is with mildly mentally handicapped people (about 75% of the retarded population). Mild retardation and related disorders seem to be strongly linked to social, cultural, and economic factors, but so are more severe forms of retardation, as well as a variety of other health problems that contribute to mental handicaps. If one includes biologically related conditions, the association is even stronger. By relying on arbitrary and simplistic definitional distinctions, we hinder efforts to prevent mental retardation and other handicapping conditions. Comprehensive and multivariate models of causation must be developed systematically.

The New Morbidity Model

The new morbidity model is derived from our multivariate analyses of causes and effects in which mental retardation is a symptom or an outcome, among others, of underlying biological and social causes. This generalized model (see Figure 1), for convenience of explanation, features poverty and perinatal factors. There is, of course, more to the new morbidity model, but low birthweight is the primary associate of subsequent mortality and morbidity. The model depicts salient variables that influence occurrence of subsequent morbidity. Portrayal of interactions among variables is important as a means of determining which children are at high risk.

For purposes of clarity of analysis and theoretical elaborations, each set of variables has a general label: *predisposing, catalytic, resource, proximal, outcome*. However, conditions occur when a variable will not be as relevant to one individual as another or when a variable might better be otherwise labeled; e.g., an outcome variable such as mental retardation could also be a predisposing variable for emotional disturbance, as with certain dually diagnosed individuals. Certainly, the categories of variables operate within a feedback loop. The model's organization is intended to begin to identify the most efficacious points of preventive intervention.

Predisposing variables are the most obvious targets for primary prevention efforts and the focus of many of our recommendations, some of which are currently under review by the Administration for policy initiatives. Poverty, acting as a *catalytic variable*, is the link between *predisposing* and *resource* variables. In this sense, poverty, particularly when chronic, serves as a catalyst to initiate or limit the operation of other variables, placing many individuals within families and many families within communities at risk for a variety of problems.

Resource variables include an array of potentially available community supports and programs to enhance the health and well-being of individuals through education, nutrition, and medical services. However, many individuals are unwilling or unable to use these resources. Proximal variables are influenced by predisposing, catalytic, and resource variables. Because many proximal conditions are immediate and life-threatening to mother and child, expensive and long-term medical interventions are often required. Negative consequences of proximal causes could be lessened or prevented by efforts directed at these other classes of variables.

Severe retardation is sometimes the *outcome* of damage to the nervous system, brought about by genetic and/or environmental factors that govern growth, differentiation, and maturation of neurons and synaptic functioning. Independent causal factors for milder disabilities are more difficult to isolate, embedded as they are in a social/cultural base in which subtle and complex interactions occur. Environmental contingencies tend to exacerbate biological vulnerability, creating a synergism in which the combination of variables is more influential than when taken separately.

Poverty

To comprehend the relationship between increasing morbidity among our children and the social/cultural context, it is imperative to examine health and social trends. Consider, first, poverty. Between 1979 and 1985, the number of people below the poverty line in the U.S. increased by 23%, while the poverty rate for infants and children (0 to 17 years) rose almost 31%. Today, 20% of our children are in families who fall below the poverty level. In 1985, children under 18 years living in female-headed single-parent families fared even worse, with over 60% in poverty; the rate is almost 70% for those in black

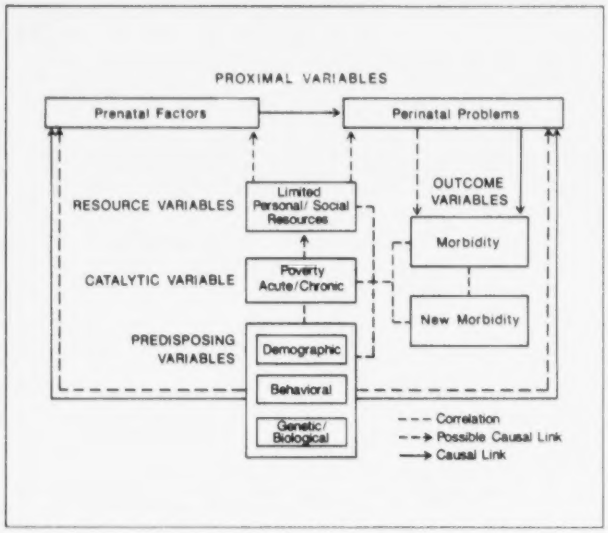

Figure 1. Generalized Model of the New Morbidity

female-headed homes. In 1987, we estimate that approximately 37 million people in the U.S. are poor.

Environmental and social factors exert a powerful force upon the intellectual, emotional, and physical development of a growing child. Recently published data show that socioeconomic, cultural, environmental, and postnatal influences are stronger determinants of mild to moderate disability than isolated biomedical factors. Today, more children and adolescents are suffering from behavioral problems, chronic conditions, and accidents, than from any single organic disease. Between 1980 and 1985, childhood mental disorders increased by 108%. Between 1970 and 1983, homicides among youth, 5 to 24 years, increased 6%. Adolescent suicides have risen every 5 years since 1950, now the second leading cause of death among teenagers. Among youth, alcohol consumption has increased by 21%, marijuana use by 16%, and those who ever used cocaine by 81%. The leading cause of death of young people, 15 to 24 years, is alcohol-related motor vehicle accidents. From 1970 to 1983, the birthrate for unmarried teens increased by more than 33%.

While conditions associated with the new morbidity affect children from all socioeconomic levels, data from numerous sources suggest that poor children are 1 1/2 to 2 times more likely than non-poor children to suffer from one or more disabilities. In the case of mental retardation, the risk is 5 times elevated.

Environments in which economically deprived children develop are less conducive to good physical, social, and behavioral development than environments of children not disadvantaged. These differences are deep-rooted, fundamental, enduring, and intergenerational. As a group, mothers of such children are not well-nourished. They received less nurturing care as children. When they have their own children, they are younger (often teenagers) and have babies more frequently. When pregnant, the general health of a woman at the lower SES range will be poorer than that of a woman who is better off. Her fetus will be exposed to greater risk of infection, intoxication, and trauma. Prenatal and general health care are less accessible to her, a disadvantage that worsens each year. After birth, babies of such mothers are, on the average, smaller for gestational age, more likely to be premature, die more readily and suddenly, are sicker in infancy, suffer a higher rate of accidents, and run a greater risk of neglect and abuse. During school years, nutrition may be inadequate, and these children miss school more frequently. Children born into such circumstances present a higher rate of learning and behavior problems and speech difficulties. Poverty is a constellation of processes cumulatively affecting developmental outcomes over time.

Low Birthweight

Of all the socially linked factors that influence infant mortality and childhood morbidity, low birthweight (LBW) is the most significant. The proportion of LBW infants in the U.S. increased from 6.7% in 1984 to 6.8% in 1985, or a total of 253,554 babies. Black infants are 2 times more likely than white infants to be born small. LBW infants are almost 40 times more likely to die during the first year. LBW infants are 3 times more likely to have neurodevelopmental handicaps and the risk increases as birthweight decreases.

Several risk factors are associated with the occurrence of LBW. Demographic risks include low SES, low maternal educational level, nonwhite race (particularly black), unmarried, and childbearing at the extremes of the reproductive age span, especially teenage pregnancy. Behavioral and environmental risks include smoking, alcohol and other substance abuse, exposure to various environmental and work-related teratogens, and stress. Perhaps the most important risk factor is the mother's failure or unwillingness to receive adequate or timely prenatal care. When one reviews these risk factors, an underlying irony emerges: the majority of these factors could be controlled to some extent.

One of our studies provides evidence of a causal connection between poverty level and birth outcomes. The current income level in the U.S. that defines family poverty (family of 4) is $10,900. The 50 states vary in the extent to which they supplement poor families to bring

them up to this level. We gathered data on each state and correlated the average monthly supplement with LBW and infant mortality. The correlations between monthly poverty level and LBW were -.50 and -.35 for whites and blacks, respectively. The correlations between monthly poverty level and postneonatal mortality and infant mortality were -.45 and -.40, respectively. The overall relationship is clear and important; its sources are more difficult to disentangle.

Prenatal Care

Evidence is overwhelming that prenatal care is a major factor in improving pregnancy outcome and lowering incidence of LBW and prematurity. This finding is strong enough to support a broad national commitment to ensuring that all pregnant women, especially those at medical or socioeconomic risk, receive subsidized high-quality care. Yet recent trends give rise for concern. From 1978 through 1982, for all women, the percentage of babies born with late or no prenatal care was 5%. In 1982 there was a 1% increase for both white and black mothers. For white mothers this figure went from 4 to 5%, and for black mothers from 9 to 10%; for teen mothers the figure is almost 12%. In 1985 these figures remain the same and so, for the fourth consecutive year, no progress has been made in reducing the number of infants born to mothers who receive late or no prenatal care.

Improved prenatal care must be a first step in our attempt to improve the health of infants and children for six important reasons:

1. Prenatal care will save thousands of infant lives and prevent needless handicaps; 75% of the major risk factors associated with LBW could be detected during the first visit and interventions initiated to reduce risks.

2. Teens are more likely to have a LBW infant; in 1984, almost 12% of infants born to women under 20 years had late or no prenatal care, and for those under 15 years, the figure was 21%.

3. We can set clear goals and evaluate progress with respect to access to prenatal care.

4. Prenatal care is cost-effective. Between 1978 and 1990, the nation will spend $2.1 billion on medical care of LBW infants during their first year of life. This amount could pay for more than 60 million WIC supplemental food packages, prenatal care for over 3 million women, maternity care (including delivery costs) for nearly 750,000 women, or basic pediatric care for almost 4.2 million infants and children.

5. A comprehensive prenatal care program could reach teens in school and the community during their first pregnancy and could be used to counsel them on how to avoid repeat pregnancies, and to provide services to reduce subsequent risk.

6. Prenatal care can be agreed upon by virtually everyone, regardless of political persuasion, religious beliefs, social status, or cultural background.

Three sets of services are so important to the health status of children and pregnant women that access to them must be assured in every community. These basic services are (a) prenatal, delivery, and postnatal care; (b) comprehensive care through age 5; and (c) family planning services. Substantial challenges that face us include racial/ethnic differentials evident for prenatal care registration, low birthweight rates, and maternal and infant mortality rates, along with indications that preventive health care services are not universally accessible or broadly used in some geographic areas, and that high-risk women and infants in need of specialized services do not always receive them. Yet these problems are not intractable and their solution will pay enormous dividends. The place to grow healthy babies is in the womb, and the home, not in the neonatal intensive care unit.

Pediatric AIDS

With the advent of pediatric AIDS, we confront perhaps the most serious childhood disorder in our history. The Surgeon General's Workshop on Children with AIDS estimates that by 1991, there will be 10,000 to 20,000 symptomatic HIV-infected infants and children in the U.S., and as many as 3,000 new infants per year will be born HIV positive. These children show neurologic abnormalities that include developmental delays, chronic encephalopathy, seizure disorders, motor dysfunctions, microcephaly, and cortical atrophy, along with other symptoms. By 1991, the in-hospital cost of caring for these infants will reach $200 to $300 million. Racial differences are highly salient; approximately 57% of reported cases are black children, 22% hispanic children, and 20% white children. It is estimated that 100,000 women of childbearing age are infected with the AIDS virus. Perinatal transmission from mothers to infants has been estimated to be as high as 50%. Most high-risk women are poor, have little education, and live in the inner city. Many who carry the virus are asymptomatic and unaware of the dangers they pose to their unborn infants. It is imperative that women in high-risk groups and of child-bearing age be given the highest priority in terms of locating and identifying them, so that intensive counseling, education, and testing can take place before a pregnancy occurs. If we can reach these women and change their behavior, we could virtually eliminate pediatric AIDS in this country. Yet once again we find that socioeconomic disadvantage plays a major

role in what is destined to become one of the most devastating health concerns of this decade, perhaps of this century, impacting on the lives of many infants and children, with no known medical solution in sight.

Problems associated with the new morbidity are complex and profound in their effect on individuals and society. If these problems are left unaddressed and unresolved, the costs, both in human and economic terms, far outweigh the costs of investing time and resources in research, treatment, and prevention. Today, as perhaps never before, we are at a crossroad regarding the welfare of children. Poverty and disadvantage have taken a terrible toll and continue to drain the potential from our most precious resource. The time is now for us to guarantee a healthy and bright future to children and, in so doing, to give a gift to ourselves as well.

Related Readings

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About RESEARCH PROGRESS

This series describes research conducted in the John F. Kennedy Center, one of twelve national centers for research on mental retardation and related aspects of human development, and is supported in part by NIH Grant No. HD-15052 from the National Institute of Child Health and Human Development.

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Volume VII, Number 1
August 1988